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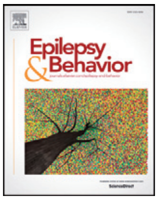

Patient perceptions of physician-documented quality care in epilepsy

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ABSTRACT

Objective: The aim of this study was to compare physician encounter documentation with patient perceptions of quality of epilepsy care and examine the association between quality and patient assessment of provider communication.

Methods: We identified 505 adult patients with epilepsy aged 18 years or older over a 3-year period in two large academic medical centers. We abstracted individual, clinical, and care measures from 2723 electronic clinical notes written by physicians. We then randomly selected 245 patients for a phone interview. We compared patient perceptions of care with the documented care for several established epilepsy quality measures. We also explored the association of patient's perception of provider communication with provider documentation of key encounter interventions.

Results: There were 88 patients (36%) who completed the interviews. Fifty-seven (24%) refused to participate, and 100 (40%) could not be contacted. Participants and nonparticipants were comparable in their demographic and clinical characteristics; however, participants were more often seen by epilepsy specialists than nonparticipants (75% vs. 61.9%, $p < 0.01$). Quality scores based on patient perceptions differed from those determined by assessing the documentation in the medical record for several quality measures, e.g., documentation of side effects of antiseizure therapy ($p = 0.05$), safety counseling ($p < 0.01$), and counseling for women of childbearing potential with epilepsy (McNemar's $p = 0.03$; intraclass correlation coefficient, ICC $= 0.07$). There was a significant, positive association between patient-reported counseling during the encounter (e.g., personalized safety counseling) and patient-reported scores of provider communication ($p = 0.05$).

Conclusions: The association between the patient's recollection of counseling during the visit and his/her positive perception of the provider's communication skills highlights the importance of spending time counseling patients about their epilepsy and not just determining if seizures are controlled.

1. Introduction

Medical and health policy communities have placed increasing emphasis on quantifying quality of epilepsy care in order to improve outcomes, with particular attention to the inclusion of patient perceptions. The Institute of Medicine highlighted these priorities in their recent annual report [1]. Chief among these priorities is the development and validation of national performance metrics of care delivery and patient perceptions.

The first approved guidelines from the Physician Consortium for Performance Improvement (PCPI), the Epilepsy Quality Measures (EQM), were published in 2011 by the American Academy of Neurology (AAN) and the American Epilepsy Society [2]. The AAN's Epilepsy Quality Measures address the quality of care as documented by the physician including assessment of seizure frequency, type, etiology, and syndrome; personalized safety counseling; and appropriate referral. These guidelines represent an excellent start but rely exclusively on chart documentation, which may be limited in application to real-world practice. These measures have likewise not been validated against patient perception of care.

In studies of care quality, physician factors such as years of experience, practice setting, and patient characteristics have been associated with EQM adherence by physicians [3–12]. As a result, the AAN's PCPI

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revised the EQM in 2014–2015 [13]. The revised quality measures reinforce the previous measures and increase emphasis on personalized counseling and education [13]. Currently, few published studies have investigated the predictive value of adherence to these revised EQM on outcomes in epilepsy care [14,15]. Increasingly, the patient experience is considered an important aspect of quality and should be cross-validated with physician-based measures of quality [16–20].

In this study, we assessed (1) physician documentation of care provided, including traditional diagnostic or therapeutic decisions and counseling; (2) patients' perceived adherence to quality metrics based on established patient report metrics; and (3) the association between these measures of quality (i.e., quality of care measures vs. patient-reported scores of provider communication).

2. Methods

2.1. Participants, screening, and recruitment procedures

We identified patients receiving care in two major academic medical centers using the Partners Healthcare System Research Patient Data Registry (RPDR). There were 4147 patients aged 18 years or older, seen in an adult outpatient neurology setting, who had at least two visits from June 1st, 2011 to May 31st, 2014 and who received a principal or secondary diagnosis code for epilepsy [ICD-10 code G40 (epilepsy and recurrent seizures) or ICD-9 codes 345.0–345.9 (epilepsy)].

We included patients if they had a confirmed diagnosis of epilepsy, were 18–85 years of age at the time of first visit, had two or more outpatient visits for epilepsy within a maximum interval of 12 months to better assess epilepsy diagnosis and establishment of epilepsy care, had been prescribed antiepileptic drug(s), and had the first visit in the Partners system after July 2011. We chose to exclude patients who had their first visit before 2011, which was the year that the quality measures were implemented, because some quality measures assess the care provided in the first visit. We excluded 3642 patients for the following reasons: 7 (0.2%) were below 18 years old, 41 (1%) were deceased at the time of data abstraction, 1983 (54%) had their first visit in the two major academic medical centers before July of 2011 or after May 31st of 2014, 501 (14%) had less than two visits,783 (21%) had no epilepsy diagnosis, 306 (8.0%) had been seen by the study investigators (LMVRM, DBH) because they were biased toward higher quality of EQM already, and 21 (1%) had no intervention for epilepsy.

We randomly selected 245 of the 505 eligible patients for a telephone interview (based on the power calculation below). The randomization process consisted of the use of computer-generated random numbers set to select 245 random digits from 1 to 505 inclusive.

We sent the selected subjects a letter (cosigned by their neurologist) describing the study and included an opt-out postcard. After excluding the 57 (23%) of 245 subjects who opted out, we contacted the remaining 188 subjects (76%) to obtain verbal consent, screen for cognitive impairment, and then complete the interview. Treating physicians informed the study team of the presence of cognitive impairment, prior to patient contact. For subjects who had a cognitive impairment based on the treating physician's judgment, we surveyed a proxy that had significant knowledge about the patient when available.

Among the 188 subjects (76%) who did not opt out, we excluded 100 (40%) for the following reasons: the treating neurologist was unreachable or declined participation (37 subjects or 15%), there was cognitive impairment with no proxy available (4 subjects, 1%), the first language was neither English nor Spanish (3 subjects, 1%), and the subject was unreachable by research staff after 3 attempts and 3 voicemail messages (56 subjects, 23%). After these exclusions, there were 88 subjects (36%) who agreed to participate, and 157 (64%) who were excluded. Among the 88 participants, 82 (93%) completed all the questionnaires; 66 patients (75%) had any epilepsy specialist involved in their care; 20 patients (23%) were managed by a general neurologist without epilepsy specialist involvement; and 2 patients (2%) were exclusively treated by a primary care physician within the study time frame of three years. Participants and nonparticipants were comparable with respect to clinical and demographic characteristics. The Partners Institutional Review Board approved this study protocol.

2.2. Procedures

Two research assistants were trained by the lead investigator (LMVRM) in the standardized abstraction of demographic, provider specialty, and epilepsy quality (EQM) data from electronic medical records. We assessed reliability by comparing three independent reviews of 20 randomly selected medical records. Interrater reliability was substantial (kappa > 0.8) on most measures (i.e., seizure frequency; epilepsy intervention; seizure type, etiology, or epilepsy syndrome; whether the clinician asked about side effects; counseling of women of childbearing age; and consideration of referral to a comprehensive epilepsy center) and moderate (kappa ranging from 0.6 to 0.8) on measures corresponding to personalized epilepsy safety counseling and screening for psychiatric or behavioral health disorders. The lead investigator resolved disagreements.

2.3. Measurements

The main independent variable in this study was quality of care in epilepsy, as defined by the AAN EQM [21]. The epilepsy quality measures were assessed in two ways: (1) physician documentation based on chart abstraction and (2) patient report during phone survey.

2.3.1. Chart abstraction

Each medical record was reviewed in its entirety. The source of demographic information was a centralized registration department, and patient care information was placed in the electronic record by the patient's treating physician. We abstracted demographic data, including age at first visit, gender, primary language, race, education level, type of insurance (private vs. public), medical center, and the involvement of an epilepsy or neurology specialist.

Neurologists with formal, specialized training in epilepsy were considered epilepsy specialists. The background of each neurologist was confirmed on the Partners website (http://www.partners.org/doctors/). All other neurologists were classified as general neurologists. A patient was identified as having subspecialty epilepsy care if seen by an epilepsy specialist at any time during the study time frame.

Abstracted clinical information included age at first seizure, epilepsy diagnosis, seizure frequency, and number of comorbidities. The duration of care was defined as the period between the first visit for epilepsy care and the last visit for epilepsy care between June 2011 and May 2014. Intensity of care was measured as the number of visits for epilepsy care within this time period. New diagnosis of epilepsy was defined as whether the patient was diagnosed and started on an antiepileptic medication within the care period. Seizure frequency was defined as the mean number of seizures during the 6 months prior to the visit. This measure was estimated based on physician documentation of patient-reported frequency, when available. When not available, this information was listed as missing data.

Disease duration was measured as the difference in years from age at first seizure to age at first visit. Baseline history of drug-resistant epilepsy was defined as a failure of adequate trials of two tolerated, appropriately selected and dosed antiepileptic drug schedules to achieve sustained seizure freedom [22].

Abstraction of the data from the medical record was standardized for each EQM (Supplemental Table e1): Seizure frequency documentation (EQM 1-A) was considered complete when seizure frequency was documented at each visit. Epilepsy intervention (EQM 1-B) was considered complete when an epilepsy intervention occurred at all visits where patients did not report being seizure-free. Epilepsy syndrome or etiology (EQM 2) was considered complete when seizure syndrome/etiology